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ABSTRACT

Although confidentiality with regard to medical records is supposedly protected by the American Medical Associaton's principles of Ethics and the physician-patient privilege, there are a number of laws that require a physician to release patient information to public authorities without the patient's consent. These exceptions include birth and death certificates, reports of wounds caused by firearms or weapons, suspected child abuse, infectious diseases, and medical information that affects performance or status in the military. In addition, medical record releases are required for insurance companies and employment. Health care reviewers, state and federal computerized "human services" data banks, and groups of professionals organized to monitor government-funded health care pose further risks to confidentiality in that they often disseminate health information to credit bureaus, employers, and educational institutions. Ironically, individuals often have difficulty in obtaining their own personal health records. In states with access statutes, individuals must sue to obtain medical records, and in states without access statutes, hospitals can legally deny an individual access. (MAI)

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FREEDOM OF INFORMATION CENTER REPORT NO. 394

ACCESS TO MEDICAL RECORDS

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Introduction

When it is considered that in 1975 an estimated 1.56 billion visits were made to physicians in this country — an average of slightly more than five visits for each American; that physician entries account for only about one-third of the total contents of medical records;[1] and that one hospital record for one patient may consist of as many as 100 or 150 pages,[2] the volume of information contained in medical records is, to quote the word often used, "staggering."

Equally staggering is the number of groups and individuals who have either authorized or unauthorized access to these records, which may contain such sensitive and potentially damaging material on an individual as his drinking habits, drug habits, sexual behavior, emotional and psychological problems, and personal and family history, as well as a wide spectrum of physical problems likely to lead to societal discrimination. Often, as a condition for employment or obtaining some benefit such as insurance, an individual must agree to the release of all or part of the information in his medical records. However, as there is no law on either the state or federal level giving an individual the right to examine all of his medical records, he frequently grants access to others without knowing what information his medical records contain and whether it is accurate.

The revelations about systematic abuses by the insurance industry and government agencies and, more recently, the controversy over access to employees' medical records in health-hazardous industries, have drawn public attention to this area. Trends such as the consumer rights movement, the changing nature of the physician-patient relationship, the re-examination of the health care industries in light of problems such as rising costs and malpractice suits, the expanding use of computers in the health field, and the near certainty that some sort of national health care plan will be instituted also have stimulated interest both in and outside the medical establishment.

The intent of this report is to examine the subject of access to medical records. The first section discusses the erosion of the physician-patient privilege as a means for protecting the confidentiality of medical records, and describes the groups and individuals who have access to individual medical records at the direct patient care stage. The second section concerns the compilation and use of medical records by those, other than the patient, who pay for medical care, and the wide array of interested parties who have authorized and unauthorized access to an individual's medical records, as well as the current surge of activity over the increasingly recognized need to safeguard the confidentiality of medical records. The third section considers the extent to which an individual has access to his own medical records. As the scope of this report is broad and the issues complex, no attempt has been made to do more than touch upon some of the major points and arguments.

Background

Medical records can be divided into three categories — the three zones used in the National Bureau of Standards-sponsored report **Computers, Health Records and Citizen Rights**, the result of a two-year study directed by Alan F. Westin, professor of public law and government at Columbia University and co-author of **Databanks in a Free Society**, a landmark study on computers and privacy.

Records in zone one, as described by Westin, are those compiled for use in direct patient care by physicians, hospitals, clinics and similar institutions, for special populations such as colleges, nursing homes, prisons, the armed forces and employers.

Zone two records are used by those who pay for health care services — the private insurance companies and government programs such as Medicaid and Medicare — to protect themselves against fraud or misrepresentation by the patient or by the physician or other health professional or institution responsible for providing the health care. Insurance companies and government agencies, in addition to requesting information from the applicant, often examine the records of those involved in direct patient care and conduct further investigations. Also included in zone two are the private and public organizations that review medical records to determine the quality and efficiency of health care and whether

Summary: This report discusses the wide variety of interested parties who compile and have access to an individual's medical records, the threat to privacy this situation poses, and the efforts being made by private and governmental groups to curb abuses of confidentiality. It also examines the lack of access most individuals have to their own medical records and the arguments for and against expanding individual access.

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the services for which the health professional or institution is being reimbursed actually have been rendered.

Zone three records, which are usually based on the information provided by direct health care records from zone one and payer and reviewer records from zone two, are put to a wide variety of social uses. Though the utilization of these records by employers and of individually identifiable records by medical researchers and those involved with rehabilitation and social welfare programs recently has been the focus of attention, there are a number of important "secondary users." Among these are the media, law enforcement agencies, public health agencies, the judicial system, and those involved in making evaluative decisions in such areas as automobile and life insurance, credit eligibility, licensing and education.

Each of these zones of medical records poses special problems for the individual, the health care provider and society.

The ethical imperative that a physician should protect the confidentiality of information given him by a patient was first set forth in the Hippocratic Oath:

> Whatsoever things I see or hear concerning the life of man, in any attendance on the sick or even apart therefrom which ought not to be noised about, I will keep secret thereon, counting such things to be professional secrets.[3]

The American Medical Association's Principles of Ethics have incorporated this, with a few exceptions:

> A physician may not reveal the confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or the community.[4]

In a 1975 judicial opinion, an argument was made for the necessity of total honesty and openness by the patient, in order for him to obtain proper medical treatment:

> Since the layman is unfamiliar with the road to recovery, he cannot sift the circumstances of his life and habits to determine what information is pertinent to his health.
>
> As a consequence, he must disclose all information in his consultation with his doctor — even that which is embarrassing, disgraceful or incriminating. To promote full disclosure, the medical profession extends the promise of secrecy. . . . The candor which this promise elicits is necessary to the effective pursuit of health; there can be no reticence, no reservation, no reluctance when patients discuss their problems with their doctors.[5]

When candidly discussing such private matters with his physician, a patient may "explicitly or implicitly" exact an obligation that the physician keep the information confidential. It is the implication that this obligation is present in "confidentiality" that leads to the "physician-patient privilege,"[6] a privilege not recognized by common law (laws made by judicial decision), though it was retained in the 1975 Federal Rules of Evidence with the provision that it "be governed by the principles of the common law as they may be interpreted by the courts of the United States in the light of reason and experience."[7] For cases involving state law, the privilege is recognized by statute in 38 states with, however, many exceptions and "waiver" provisions.[8]

It should be noted that privilege applies only to judicial proceedings. A communication is privileged "if the person to whom the information is given is forbidden by law from discussing the information in a courtroom without the consent of the person who provided it."[9] This privilege belongs to the patient, not the physician or health care provider,[10] so that, in malpractice litigation for instance, the physician cannot use the privilege to withhold subpoenaed records. According to Dr. Maurice Grossman, writing in the **Annual Review of Medicine**, "The process of legal erosion has reduced this protection — physician-patient privilege — to virtual impotence."[11]

Therefore, neither the American Medical Association's Principles of Ethics nor the physician-patient privilege, where it is recognized by law, protects the information an individual has confided to a physician, if the physician is required by law to disclose confidential information, is authorized by the patient to do so, or is involved in professional communications where there is no "confidentiality," as in the case where an individual "knowingly goes to a physician for a report to be made to some other party."[12]

This last category includes voluntary and involuntary medical examinations, but, as will be discussed later, how "knowingly" the patient goes to some of these and whether specific promises of confidentiality are honored are subject to debate. Obviously, the information in medical records is not protected if attempts are made to procure it illegally, as when the White House "plumbers" burgled the office of Daniel Ellsberg's psychiatrist following the publication of the Pentagon papers, in an effort to obtain Ellsberg's psychiatric records.

There are a number of laws that require a physician to release patient information to public authorities, and the individual patient has no control over the release. Foremost among these are the public reporting laws in existence in almost all states. Under these, birth and death certificates and, in some states, a fetal "birth" certificate in the case of abortion or miscarriage, must be filed, though a New York statute requiring this recently was declared an unconstitutional invasion of privacy.[13] Suspected child abuse, wounds caused by firearms or wounds likely to result in death caused by sharp or pointed instruments, and diseases that are infectious, communicable or contagious also must be reported. A California statute requires that any disease that might cause "lapse of consciousness," such as epilepsy, be reported.[14]

Some state laws allow the disclosure of information without the permission of the patient if it is judged by the physician to be in "the best interests of the patient." The New Jersey statute protecting the physician-patient privilege includes the provision that:

> Nothing in this section shall preclude disclosure upon proper inquiry, of information as to a patient's current medical condition to any relative or friend. . . if it appears that the information is to be used directly or indirectly for the benefit of the patient.[15]

Normally, patients have no objection to having a physician reveal medical information to their families, but, according

to Grossman,

> Physicians have learned that in some families the dedication to each other leaves much to be desired. Sensitive information divulged to a parent, child or spouse has been used destructively against the patients.[16]

He suggests that it might be a good idea if it were established at the outset whether confidentiality was to be "absolute, conditional or none."

Recent legislative trends have been giving physicians the legal right to treat minors without parental consent, eliminating a further exception to confidentiality. Laws have been directed at treatment in such sensitive problem areas as venereal disease, pregnancy, contraception, alcoholism and drug abuse. Forty states have legalized all treatment without parental consent,[17] and 49 have legalized treatment for venereal disease.[18] However, the investigation of communicable diseases and reports on pregnancy and abortion might lead to attempts to contact a minor at his or her home address, in which case it is likely that the parents would be alerted.[19]

Another legal exception to physician confidentiality is the Tarasoff case obligation. This obligation resulted from a case involving Prosenjit Poddar, a student at the University of California's Berkeley campus. While receiving outpatient psychotherapy at the Cowell Memorial Hospital of the University of California in 1969, Poddar began threatening to kill Tatiana Tarasoff, a fellow student. His therapist, seeing the threats as constituting a possible danger, asked the campus police to take Poddar into custody, incident to legal action being pursued to involuntarily commit Poddar for hospitalization. At the time the request was made, Tarasoff was in Brazil for the summer and, although the police took Poddar into custody, they released him after finding no indication that he was dangerous or abnormal.

Poddar stopped going for treatment after he was taken into custody, but caused no disturbances and even began rooming with Tarasoff's brother. However, a short while after Tarasoff returned from Brazil, Poddar did kill her. Tarasoff's parents filed suit against all the individuals involved and the Regents of the University of California for a "wrongful death." They based their suit on four legal grounds: One was that the defendant had failed to warn Tarasoff's parents that she was in danger.

The action was dismissed by the lower courts on the grounds that the defendants legally were immune and because of the "overriding need to maintain confidentiality in psychotherapy."[20] The California Supreme Court reversed the decision of the lower courts and ordered that the case be tried, stating in effect that "psychotherapists have a duty to warn potential victims when they determine that their patient is dangerous."[21] The defendants, along with professional societies, petitioned the court for a rehearing, which was granted. The professional societies maintained that violating confidentiality under the circumstances present in the Tarasoff case would interfere with effectively treating all patients and cited studies which showed the probability to be 99 out of 100 that a judgment of dangerousness in the case would have been erroneous. The Supreme Court of California filed a revised decision on July 1, 1976, which retained the obligation that a warning be given. According to Grossman, the decision in this case

> destroyed an important element in protecting confidentiality. It changed the medical ethics and legislative intent from "no privilege" or "may disclose" to "must disclose," when the physician foresees a potential hazard to a third party.[22]

Military physicians have a special obligation to report to military command any medical information they think is likely to affect the performance or status of any member of the armed forces. According to Captain Knoll of the Judge Advocate General Corps,

> Military law, quite simply, does not recognize the physician-patient privilege. . . . A military doctor performs examinations as part of his official duties, and information thereby acquired would be official.[23]

Unless a court-martial is pending, medical information can be used against a member of the armed forces without warning.

One example of such use is that until March 1974, when the program was discontinued, separation code numbers were put on honorable and general discharges that, unknown to veterans, signaled to employers and others such coded medical information as the following:

> Codes 249-257 — homosexuality; 261 — psychiatric or psychoneurotic disorder; 274, 277, 278 — physical disability, not entitled to severance pay; 287 — unclean habits, venereal disease; 288 — anti-social behavior; 289 — alcoholism; 361-362 — homosexual tendencies (without overt homosexual acts); 369 — cyclothymic personality (manic depression); 375 — failure to meet fitness standards; 384 — drug abuse; 386 — sexual perversions; 41E — obesity; 46B, 46D — sexual deviate; 460 — schizoid personality; 480 — personality disorders; 522 — court-martial, homosexual; 651 — physically disqualified.[24]

More than 400,000 Vietnam veterans were given separation numbers such as these. Although separation code numbers no longer are being issued, if a veteran wants the code deleted from his discharge, he must make a specific request. As Westin points out,

> Since the majority of veterans probably still do not know the meaning of the numbers, hundreds of thousands of them are carrying around this information and disseminating it to employers' files.[25]

Whether a physician-patient privilege actually exists between company doctors and employees is a matter of some controversy. Larger companies often offer health services, either periodic screenings or more extensive examination and treatment. Most employers designate as confidential employees' medical records. However, at a Washington conference in October 1977, Anthony Mazzochi, legislative director of the Oil, Chemical & Atomic Workers International Union, said that medical privacy "doesn't exist" for employees and that industry's arguments that it does are hypocritical. He said, "Corporations know precisely what is in their employees' medical records," and they use the records for demoting, transferring and dismissing employees found to have chronic illnesses by company doctors.[26]

Dr. Norbert J. Roberts, medical director of Exxon Corporation, said that so far as his company was concerned, "Quite a normal physician-patient relationship can exist." He said, "No doctor goes to medical school with the idea that he's going to work for Exxon. They want to help people."[27]

Westin calls IBM Company "a good example of a large corporation's occupational health program in which special attention has been given to the rules for information use."[28]

These exceptions to the physician-patient privilege, where disclosure is required by law and where physicians employed by institutions do not or are alleged not to recognize it (military and company doctors are only examples), are specific and well-defined, when compared with the third exception. This, as was previously mentioned, is information the physician is authorized by the patient to disclose.

When applying for insurance or employment, in order to be considered eligible, an individual often must sign a form giving "blanket" or general consent to the release of all of his medical records. What insurance companies and other second zone users do with this information and the transferral of information to third-party users, as well as the legislative and judicial trend toward "informed" rather than "blanket" consent, will be discussed later. The important point to be made here is that once an individual signs a paper authorizing the release of information contained in medical records maintained by his physician, neither he nor the physician has any control over what happens to the information or who subsequently has access to it.

In hospitals, there is far less confidentiality than in private physicians' offices and, often without being aware that he has done so, a patient just by being in the hospital gives his "implied consent" to letting hospital staff not directly involved in his care have access to his medical records. This "implied consent" covers such personnel as nurses, medical students, interns, residents, financial workers, social workers, secretaries and researchers. Personnel other than the physician treating a patient may add information or comments to the patient's medical records; this is especially true in psychiatric hospitals, where aides and clerks may add comments and nurses may make notes on the patient's fantasies, plans for the future, moods and interaction with other patients and staff members.[29] According to two sociologists,

> The presumption in psychiatric facilities. . . is that there are no areas in the patient's life (and for that matter, no areas in the lives of his associates) that lie beyond the legitimate interest of the institution.[30]

Though, particularly in psychiatric hospitals, attempts are made to protect the confidentiality of medical records and despite the fact that this is one of the articles in the American Hospital Association's Bill of Rights, leaks do occur. The leaking of information on Sen. Thomas Eagleton's psychiatric history after he was selected as George McGovern's running mate for the 1972 presidential campaign is one well-publicized instance.

As a rule, hospitals will give out "minimal" information without the patient's consent, but, according to Westin, case law indicates that as long as the press commits no crime in obtaining medical information, they can publish it without penalty if there is a "legitimate public interest" in it. Also,

> The press will not be held as accessories for receiving stolen goods because the courts will generally find that what they received was "information," the actual documents having been copied and replaced.[31]

Where publication can be construed as commercial exploitation or advertising, however, suits against publishers have been won, as was the case in 1939 when a young woman sued **Time** magazine for publishing a story about the treatment she was receiving for uncontrollable gluttony and was awarded $1,500. Westin states that "there is no reported U.S. case in which a physician or hospital has ever had to pay money damages for breach of confidentiality."[32]

Theft of confidential information from hospitals is eminently possible, and the media are not the only ones responsible, as is shown by the indictment of the Denver-based private investigative firm Factual Services Bureau, which had been in operation for at least 25 years. Among the techniques used by the bureau to illegally obtain confidential information were (Los Angeles **Times**, 6-12-76) impersonating doctors and nurses over the telephone, the easiest and most successful technique; writing bogus letters asking for information; dressing as clerics; and paying people within the hospital to act as "source agents."

Factual Services Bureau, which had offices in 15 cities throughout the country, sold (New York **Times**, 12-16-76) the information it stole to insurance companies. Although the bureau is now defunct, a former employee, W. J. McIntyre, is (Miami **Herald**, 1-22-77) president of Inner Facts, a firm that operates out of the same Chicago office building as a Factual Services branch office, using the same phone number.

If an individual signs a "blanket" consent form on an insurance application, the insurance company has access to all medical records, including hospital records. Also, hospitals often require, as a condition for admission, that the patient sign a "blanket" consent form authorizing the hospital to release information to anyone "it thinks should have it."[33] This includes private insurance companies as well as the other zone two users, government health funding programs and monitoring agencies, and zone three researchers.

As with physicians' medical records, once the hospital releases information from a patient's medical record, either as a result of the consent form the patient signed at the time of admittance or as a result of a separate authorization given by the patient to an employer or insurance company, it has no control over who has access to the information.

The expanding use of computers in physicians' offices and hospitals often is seen as a further threat to the confidentiality of medical records. Computers offer physicians the opportunity to record more in-depth information on their patients, but only a small percentage of physicians have computer services available in their offices, and the majority of these use the computers for administrative tasks rather than for patient care. Spokesmen in the computer and health fields expect computer use to gradually increase in physicians' offices in the next few years, an increase Westin attributes largely to the lower costs for small-system computers and minicomputers.[34]

A 1974 survey by the American Hospital Association showed that nearly every hospital in the country had computerized some aspect of its operations, though only one-quarter of the hospitals, usually the larger institutions, had an in-house computer.[35]

Zone Two and Zone Three Users

As the use of zone two and zone three medical records is a broad and rapidly changing area, no attempt will be made

here to do more than give some indication of the major issues and trends. The chief point being made is that once medical records leave the health care provider, their use mushrooms.

Private health insurance companies have applicants fill out forms that ask for a complete description of their medical history, current mental and physical state of health, life styles and personal habits. This information is kept as a permanent record and often is coded and stored in a computer for future reference. In some cases, the insurance company decides to investigate the applicant and uses its authorization, which the applicant provided by signing a consent form, to check his medical records. Often, independent investigative firms such as Hooper-Holmes and Equifax are employed by the insurance companies.[36]

Investigators, in addition to examining physician and hospital records, obtain unconfirmed information from "neighbors, friends, family, employment sources and wherever the claimant has contact."[37] Much of this information never is verified, and John E. Gregg, a "veteran insurance man" and former FBI employee, testified (New York **Times**, 10-7-73) before a Senate subcommittee in 1973 that at least 40 percent of the information stored by insurance companies is "defective and erroneous."

It should be noted, however, that the erroneous information does not always originate with the insurance company. An informal study found that hospital nursing staff sometimes check "out of wedlock" on a child's birth certificate if they do not believe a mother's assertion that she is married and, in larger institutions, may record illegitimate births as legitimate.[38] Another example is (St. Louis **Post-Dispatch**, 1-14-77) that of a San Francisco woman who, in order to have an abortion prior to 1973, had a doctor certify that her mental health would not enable her to safely sustain a pregnancy, but then she was unable to get the hospital to return the letter.

Information obtained from the insurance investigation into the medical records and personal contacts of the applicant, and possibly from further investigations when claims are submitted, is retained and may go to the Medical Information Bureau, which stores computer records on the health history and insurance claims of 11 million Americans and makes them available to the 700 member insurance companies.[39] Ninety percent of the MIB's information is (Los Angeles **Times**, 3-22-74) medical, and the remainder relates to a person's "character and morals." A code signaling a problem, medical or otherwise, is supposed to prompt further investigation of an insurance applicant, but the applicant often is rejected on the basis of the code alone. MIB, though not subject to the Fair Credit Reporting Act, has, however, agreed to comply with its individual access provisions.[40]

Where government health payers such as Medicaid and Medicare, health care reviewers, and government agencies such as the National Institute for Occupational Safety and Health are involved, as well as in medical research, the issue is the use of individually identifiable records without the informed consent of the patient. Recently an amendment to the Medicare-Medicaid Anti-Fraud and Abuse Bill that would have "prohibited all federal access to records of private sector patients without patient authorization" was defeated.[41] The threat seen here is that information obtained from such programs as Medicaid and Medicare is being stored in state and federal computerized "human services" data banks.

Another innovation some find disturbing is the Professional Standards Review Organization, created by Title XI of the 1972 Social Security Act to monitor government-funded health care. PSRO is a network of local and regional groups consisting largely of medical professionals and, although it presently reviews only those hospitals treating Medicaid and Medicare patients, it is expected to eventually review all institutions providing government-funded health care. If there were a national health care system, PSRO might be responsible for monitoring all health care providers and therefore would have access to the medical records of every American.[42]

Information from zone two payers and reviewers makes (St. Louis **Post-Dispatch**, 9-10-76) its way to zone three because, as Arthur J. Snider puts it, "There are many people who want to look at your medical records," and "despite security precautions, information does leak to unauthorized persons." Dr. Jerome S. Beigler, chairman of the American Psychoanalytic Association's committee on confidentiality, said (St. Louis **Post-Dispatch**, 9-10-76) that the sources of most leaks are probably insurance documents.

The following actual cases probably best illustrate (St. Louis **Post-Dispatch**, 9-10-76) the consequences of information from medical records becoming available to certain third zone users:

> A West Coast surgeon hospitalized for a mild heart attack returned home to find his automobile liability insurance suddenly had been canceled. No one had examined him to determine if there was any change in his capability as a driver. He is even unable to determine how the auto insurance people found out he had a heart attack.
>
> An accountant, a cancer victim, learned that an investigator for a credit bureau visited the homes of neighbors to learn if the operation had injured his work potential. He had filed an insurance claim for reimbursement of hospital expenses. How did the credit agency get the information?
>
> A file clerk lost a promotion. A fellow employe told her it was because she was seeing a psychiatrist and that she had learned about it from friends who worked in the personnel department and processed insurance forms.

In some instances, the dissemination of information from an individual's medical records leads to a situation where the individual is almost literally the last to know. One woman who had received shock treatment in a hospital for schizophrenia was judged to be in too fragile a condition to be told her diagnosis, but a report, including the diagnosis and an account of the woman's suicide attempt, was sent by the hospital to her insurance company. As she was insured through her employer's group contract coverage, the insurance company sent the report to her employer, so that when the woman returned to work, she discovered that her fellow employees knew all about her illness. The woman became "paranoid toward her physician and terminated treatment."[43]

Abuses of confidentiality recently have been receiving so much attention that any generalizations from what have been policies in the past are dangerous. Two major studies on the subject have been commissioned and completed. The Privacy Protection Study Commission was created by the Federal Privacy Act of 1974 to study record-keeping and privacy on state and local levels in a number of areas, including medical records. The National Bureau of Standards sponsored the report by Alan F. Westin, which has been

drawn upon extensively in this paper, **Computers, Health Records and Citizen Rights**. Both studies have made recommendations. The American Medical Association has issued guidelines and drawn up a Model State Bill on Confidentiality of Health Care Information. The National Commission on Confidentiality of Health Records, a watchdog commission that as of January 1977 had 18 national health and medical organizations as chartered members,[44] was established in 1976 and has been holding conferences, making recommendations and putting out a newsletter. The Mental Health Law Project was successful in getting Blue Cross/Blue Shield, which together account for more than 40 percent of all private health insurance,[45] to change their federal employees' mental health claims form.[46] Ralph Nader's Health Research Group has been playing an active role. These are only a few of the organizations that have become involved.

Medical records also have come to the attention of Congress. As of the end of 1977, 12 privacy bills had been introduced since the Privacy Protection Study Commission report was issued.[47] State legislatures have been considering the matter and sometimes taking action, as in New York, where a Confidentiality of Medical Information Act was introduced last year.

Legislation varies greatly, but the trend is for the duty of protecting the confidentiality of medical information to be extended by law to third parties holding medical records. Also, there has been a movement to require "informed consent" for the release of medical records, rather than "blanket consent." Informed consent, at least according to the New York law, "must specify the nature or extent and purpose of the disclosure and the names of the parties involved. The consent is subject to revocation and is time-limited."[48]

According to the National Commission on Confidentiality of Health Records,

> Recent court cases promise to set precedents in striking the delicate balance between the patient's interest in keeping his medical problems private and the interests of insurers, employers and the government in finding out as much as they need, in order to discharge their respective functions.[49]

Balances are being sought and safeguards, prohibitions and sanctions proposed, but, as illustrated by the Social Security Administration's success in penetrating its own supposedly fail-proof system of safeguards designed to prevent unauthorized access to computerized information on thousands of Medicare patients, there will always be (Washington **Star**, 1-31-77) leaks.

Individual Access to Medical Records

Though, as has been shown, a wide range of interested parties has access to an individual's medical records, the individual often is denied access to them.

Some states have statutes giving individuals a legal right to view and copy their own hospital records, usually with restrictions. In Tennessee, hospital records are closed to a patient except when opened by a court order or when "good cause" is shown by the patient. In Louisiana, a patient may request copies of treatment from a "public hospital." In Illinois, "most public and private" hospitals must provide copies of hospital records to "former patients."[50]

The most liberal statute is the Massachusetts statute, which gives patients an absolute right of access to hospital records both during and following their stay. However, a recent test study showed that, despite the statute, the majority of Massachusetts hospitals continue to deny patients access to their medical records, leaving patients no recourse but to bring suit.[51]

In some states, access to hospital records is limited to the patient's attorney or an authorized representative such as a physician. Where there is no access statute, patients must sue the doctor or hospital and get a court order, which usually is obtained by suing for malpractice. In 1973, an HEW commission found that the need for a court order to gain access to personal medical records increased "the incidence of unnecessary malpractice litigation."[52] No states have statutes granting patients access to medical records kept by private physicians in their offices.[53]

Courts have held that ownership of the original medical records of a patient rests with the physician or hospital. In one case, a physician provided in his will for the destruction of all his professional records. Several of his former patients brought a suit before a New York court, which ruled that the records belonged to the doctor's estate rather than the patients, but that, as a matter of ethics, the records must be turned over to the succeeding physician. The court also said that the records were to go to the succeeding physician instead of the patients, because only a physician was qualified to read and interpret medical records.[54]

Another ownership case, brought before the Supreme Court of Michigan, involved X-rays made of a workman's occupational injury. The workman's employer refused to pay the fee unless he were given the X-rays; the physician refused to give the employer the X-rays and sued for his fee. The court determined that X-rays were of value to the physician but meaningless to a layman and therefore ruled that, if there were no agreement to the contrary, X-rays were the property of the physician who took them incident to treating the patient.[55]

The Judicial Council of the AMA in its **Opinions and Reports** set forth its policy on medical records:

> The Principles neither intend nor require that a physician give a copy of his records to his patient. These records are primarily the physician's own notes compiled during the course of diagnosis and treatment so that he may review and study the course of the illness and treatment. The records are medical and technical, personal and often informal. Standing alone they are meaningless to the patient but of value to the physician and perhaps to a succeeding physician.[56]

Appellate courts have ruled, however, that though a physician or hospital owns the original medical record, the patient's interest in the information contained in the record is so vital to him that he has a right to it. In access cases involving general hospital records, the courts have given patients access, but this has not been true for all cases involving psychiatric hospital records. No cases have been recorded where a patient has directly sued a private physician's office for access to his medical records.[57]

In general, since in states with access statutes individuals often must sue to obtain medical records and, in states without access statutes, hospitals legally can deny an individual access, the individual has no access to hospital or physician's records unless he sues or the physician or hospital decides to grant him access.

Harold L. Hirsh, M.D., J.D., in an article in the 1975 **Legal Medicine Annual**, states that a contractual arrangement between the patient and the health care provider in regard to access to medical records does not violate any laws or public policy and that similar contractual arrangements have been recognized by the courts. He says that:

> Just as the physician or hospital may require a written request for the transmittal of the patient's record, so can the patient request a written affirmation by the health care provider that he will provide the patient with a copy of his record within a reasonable time depending on the urgency of the circumstances. The patient may be required to provide a formal request and pay the administrative costs incident to the preparation of the record.[58]

The obvious drawback in gaining access to medical records through a contractual arrangement is that a health care provider simply can refuse to enter into such an arrangement and, if the patient insists upon it as a condition for treatment, can refuse to treat the patient.

There are a few categories of medical records to which the individual has legal access. In Maryland, an individual may demand access to the medical files maintained on him by an insurance company, though "information provided by a physician for placement in these files may be withheld for five years."[59] Elementary and secondary school records, including medical records, are open to the parents of the individual and to the individual if he is over 18, under the so-called Buckley Amendment.[60] The Federal Privacy Act of 1974 and fair information practices acts in five states give individuals general access to records, including medical records, maintained by federal and state agencies. Also, according to Westin, there has been a trend in some state courts to recognize a need for patients to have information about their treatment, in order to give or refuse consent or choose between alternate treatments, and to view the physician-patient relationship as "a decision-making partnership instead of a medical monopoly."[61]

"Therapeutic privilege" still allows a physician to withhold information about diagnosis and treatment if the physician, on whom the burden of proof rests, can prove that disclosure would upset the patient to such a degree that he would be unable to weigh the risks of his treatment. Under ordinary circumstances, a patient is presumed to have the right to full information about diagnosis and treatment, though not to all the information in his records.[62]

Conclusions

The physician-patient privilege and the ability of the physician to protect the confidentiality of a patient's medical records have eroded to the point where the physician has little control over the records, except where patient access is concerned. Few would argue that physicians, hospitals, insurance companies, government-funded health programs, health reviewers, and medical researchers do not have a legitimate interest in some medical information from a patient's record. The issues for these users have been the extent to which they have access, how they protect the records in their care, and to what other uses they put these records. Access by groups such as law enforcement and investigative agencies, employers, credit agencies, educational institutions and others is often a clear violation of the privacy of an individual and damaging to his interests. Centralization of data in computer banks does pose serious threats. However, the problem of confidentiality of medical records has come to the attention of the public, a wide array of organizations, state legislatures and Congress. It is probable that the more flagrant abuses will be eliminated, even if complete confidentiality is impossible.

Individual access to personal medical records remains a controversial issue, with many reasons being presented for and against giving blanket or unrestricted access to the individual.

Individuals, it is argued, cannot give informed consent to the release of their medical records if they do not know their contents and whether there are damaging falsehoods and inaccuracies. Though they pay for the compilation of many of their medical records, they are not able to see the results of lab tests and examinations for which they are paying. The specialization of physicians and the increasing mobility of Americans mean that doctors retain records that are worthless to them but valuable to the patient.

The basic argument for blanket access is, however, the patient's right to know information of vital interest to him, information that proponents say can be written in language the individual patient can understand and is competent to handle.

Among those favoring giving the individual blanket access are some physicians. In a 1973 **New England Journal of Medicine** article, Dr. Budd N. Shenkin, along with non-physician David C. Warner, advocated giving all patients a complete and unexpurgated copy of all their medical records.

Shenkin and Warner contend that physicians would benefit from having better informed patients, who, since they would have greater choice as consumers of health care and would understand their diagnosis and treatment more fully, would be more satisfied and cooperative. Also, they say that physicians, with more information available on the patient, would be able to provide better treatment and more continuous care and would have greater incentive for practicing high-quality care because of more peer review of their records. They see the quality of records and care and the productivity of physicians increasing as a result of patient access. They say that better education of patients through access to records is likely to curtail, rather than increase, dangerous attempts at self-treatment.

Where patients are terminally ill, Shenkin and Warner suggest that patients frequently would be better off knowing, but that

> flexibility would be possible. Circumlocution on the record would allow the patient to deny if he wished. The physician and patient could agree before the results were known to tell or not to tell. A patient himself could decide not to look. The only excluded possibility would be the physician's withholding information the patient desired.[63]

Dr. Sidney Wolfe, director of Ralph Nader's Health Research Group, was quoted in the Milwaukee **Journal** (1-23-76) as saying that he did not think medical records were too technical for patients to understand. "People don't have to be taught to do an appendectomy to understand medical records. . . . To use that as an excuse is to say a medical record has to be written in an obscure way."

Most physicians, however, including AMA President John H. Budd, oppose giving patients blanket access to medical

records. Their argument is that medical information is too technical for patients to understand and might lead to misinterpretations or attempts at self-treatment. Furthermore, it is argued, if physicians knew patients would see their medical records, they would alter their records accordingly and the records consequently would be less useful. Basically, their argument is that disclosure of some medical records to some patients may cause emotional distress to the patients and prove destructive. They say it is their ethical duty to do what they believe is in the best interest of the patient, and they must be able to exercise professional discretion in determining whether it is in the best interest of the patient for information to be divulged or withheld.

The Privacy Protection Study Commission has recommended that where there is disagreement over a patient's gaining access to his medical record, a third party should be brought in to adjudicate. The chairman of the National Commission on Confidentiality of Health Records has specified that this third party should be a "health care professional."

Westin has recommended that if a physician believes access to medical records is not in the patient's best interests, the following procedure should be used. The physician should explain why he does not wish to release the information and, if the patient still wants to see his records, offer to submit the records and decision to a physician of the patient's choice. If the patient rejects this option, the physician should disclose the information to him. For psychiatric records, the same procedure would be used, except that if the therapist felt strongly that the information should not be disclosed to the patient, he could terminate therapy with the patient without releasing the records, in which case the patient could sue for access.

Studies have been done on the results of giving hospital patients access to their medical records. One, published in the **Archives of Physical Medicine and Rehabilitation**, concluded that "most patients reacted positively to the receipt of the written record" and none were apparently harmed by being offered the record, although some "chose not to deal with the record." However, though no factual material was withheld from the record, except in one case where the spouse communicated the information instead, modifications were made in the language used in 10 percent of the cases.

> In four instances, the prognosis was stated in a less discouraging way than it might have been otherwise. In three instances, the word "tumor" was used instead of "cancer." In five instances, a psychiatric label was avoided and the problem stated in terms of behaviors or feelings.[64]

All reports were carbon copies of the hospital records and routinely offered to the patients.

Another study, carried out in Australia and published in the **Annals of Internal Medicine**, reported the following:

> The effect of giving hospitalized medical patients access to their problem-oriented hospital records was investigated. Twenty-five subjects were given free access to their records while 25 other subjects served as controls. Few of the open record group actively sought and studied their records; most elected to see them only as a part of routine ward rounds; and one objected to seeing the record at all. Taking the experimental group as a whole, there was no measurable effect of seeing the record on the subjects' ability to list their diagnoses or medications, their self-assessment of depression, anxiety or contentment, or their attitude toward selected components of the health care system. On the other hand, in individual instances access to the hospital records seemed to facilitate communication and provide an opportunity for hospital inpatients to monitor objectively their hospital course.[65]

The recommendations of the study were that,

> the opportunity to review a problem-oriented hospital record might be offered to all patients with a modest level of intelligence and ability to read and that the patients' preferences are appropriate to determine patients' access to their own medical records, provided that health care personnel are aware that what they write may be reviewed by their patients.[66]

More studies almost certainly will be done on this subject, but as the scope of each study is, of necessity, narrow, it is doubtful that a consensus will be achieved in the near future on the advisability of giving unrestricted access to personal medical records to individuals. Beneath the differing views and recommendations, however, lies the basic question of whether an individual living in a democracy should ever be denied information of vital importance to him, for what has been judged to be his own good.

FOOTNOTES

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4. **Ibid.**, p. 20.
5. **Ibid.**
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8. **Ibid.**, p. 20.
9. **Ibid.**, p. 21.
10. **Ibid.**
11. Grossman, "Confidentiality," p. 44.
12. **Ibid.**, p. 47.
13. Westin, **Computers**, p. 21.
14. **Ibid.**
15. **Ibid.**, p. 23.
16. Grossman, "Confidentiality," p. 48.
17. **Ibid.**
18. Westin, **Computers**, p. 23.
19. Grossman, "Confidentiality," p. 49.
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21. **Ibid.**, p. 50.
22. **Ibid.**
23. Westin, **Computers**, p. 33.
24. **Ibid.**, p. 34.
25. **Ibid.**, p. 66.
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29. **Ibid.**, p. 16.
30. **Ibid.**
31. **Ibid.**, p. 25.
32. **Ibid.**, p. 26.

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